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ABSTRACT

Tourette Syndrome is conceptualized as a neurobehavioral disorder, with behavioral aspects that are sometimes difficult for teachers to understand and deal with. The disorder has five layers of complexity: (1) observable multiple motor, vocal, and cognitive tics and sensory involvement; (2) Attention Deficit Hyperactivity Disorder; (3) obsessive-compulsive disorder or ritualistic behaviors; (4) stereotypical behavior; and (5) associated learning disabilities. Added to this is an emotional overlay of anxiety, fatigue, embarrassment, and depression. Classroom recommendations are presented for use in working with students exhibiting Tourette Syndrome, in the areas of environmental structure and planning, visual motor impairment, attention deficit disorder and impulse control, obsessive compulsive symptoms, cognitive and learning disabilities, emotional overlay, and testing considerations. (Seven references) (JDD)

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A Complex Neurobehavioral Disorder Which May Involve Learning Problems, Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Symptoms, and Stereotypical Behaviors:

Tourette Syndrome; Overview and Classroom Interventions

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ABSTRACT

A COMPLEX NEUROBEHAVIORAL DISORDER WHICH MAY INVOLVE LEARNING PROBLEMS, ATTENTION DEFICIT HYPERACTIVITY DISORDER, OBSESSIVE COMPULSIVE SYMPTOMS, AND STEREOTYPICAL BEHAVIORS: TOURETTE SYNDROME; OVERVIEW AND CLASSROOM INTERVENTIONS

Tourette Syndrome (TS) is a neurobehavioral disorder primarily recognized by motor and vocal tics. However, the syndrome also can manifest in extremely complex and subtle behaviors which the diagnostic criteria fail to adequately explain. Consequently, teachers and administrators don't recognize these behaviors as part of the syndrome, and are caught unprepared in appropriately addressing these behaviors in the classroom. The resulting misunderstanding can wreak havoc for both student and teacher. Based on vast experiences with hundreds of TS suffers over the past eight years, presenters will describe the behavioral nature of TS, beyond the obvious tics. Description will be supplemented with videotaped vignettes of children who exhibit TS, giving their personal accounts of the syndrome and their often devastating school experiences. Some revelations will be shared about the relationships between TS, learning disabilities, Attention Deficit Hyperactivity Disorder, Obsessive Compulsive symptoms, and even some stereotypical behaviors most often associated with autism. Presenters will describe pilot programs which have been found to successfully circumvent some of the complex problems, and which have been solicited all over the country, due simply to the fact that they are effective. Handouts listing and describing classroom interventions will be provided and discussed. These interventions have been uniquely designed with the perspective of both teacher and student in mind, and offer a truly useful guide in meeting the classroom needs of both. Time permitting, question and answer session will follow presentation.

DEFINITION

Most of you may be aware that Tourette Syndrome is considered a neurological disorder, characterized by motor and vocal tics. You will hear all sorts of definitions for Tourette Syndrome. We prefer to conceptualize it as a neurobehavioral disorder because initially it was recognized as a neurological condition, and still is. But over the course of time we know more and more about Tourettes. As a result there are lot of behavioral aspects of the disorder that were previously not associated with Tourettes. In other words, teachers would say, " I know the child has motor tics, but it is his behavior that I will not tolerate in the classroom." So that is what we try to address because as a neurobehavioral disorder it is the behavioral aspects that make it most difficult for the teachers to deal with and understand.

LAYERS OF COMPLEXITY

By and large, most people who have Tourette Syndrome are ordinary, healthy individuals with some peculiar mannerisms. For the most part, few if any modifications are required in the classroom for these individuals in addressing their Tourette symptoms. However in some individuals the syndrome is pervasive and involves cognition and behavior that may affect school performance. The disorder as we conceptualize it has basically five layers of complexity, similar to the structure of say, " les mille-feuilles", a French pastry. The five layers, or dimensions, are as follows:

First Dimension

The first dimension of Tourettes is composed of observable motor tics, which may be just the tip of the iceberg, in more pervasive cases. Motor tics are the simplistic aspect of Tourettes, in a sense . The ones most frequently presented are rapid, repetitive eye blinks, shoulder shrugs, or head shakes. One of the diagnostic criteria for Tourette, as opposed to simple tic disorder, is that multiple motor tics must be present. Oftentimes the child exhibits not only motor tics, but also vocal tics. These may be compulsive and repetitive clearing of the throat, sniffing, grunting, yelping, barking, or more complex vocalizations such as the repetition of words and phrases, echolalic behavior, or the more sensational coprolalia, which is the utterance of socially unacceptable words or phrases.

In addition to the motor and the vocal tics you also have a cognitive component, in that inner thoughts also fire randomly in a compulsive, repetitive way, in the same manner as motor and vocal tics do. Just as the child gets into a repetition of motor activities such as an eyeblink or shaking of the head, he also gets into a cognitive repetition, and involuntarily processes a thought over and over again. This can be in the form of, for example, excessive proofreading. Or when looking at the board, with say, four steps to copying a math problem, the child gets locked into looking at step two, then back at the board, then back at step two, then back at the board, and so on. He then can get into a type of enjoyment or sensory involvement with his tics. One young man relates his experience with this sensory involvement, saying, "I have to do the behavior and do it enough, and then I start to like how it feels and then it becomes a habit and I can't stop it."1 To summarize, the first layer or dimension of Tourettes, the observable motor tic is the one we see, the observable vocal tic is something we hear, but there is also the hidden, or cognitive "tic," and the sensory involvement just addressed. All of this comprises the first, most obvious dimension of Tourettes.

Second Dimension

Additionally, you can likely add the associated Attention Deficit Hyperactivity Disorder (ADHD) which is very often seen in conjunction with a Tourettes diagnosis. Average estimates cite 50% of children with Tourettes exhibit cognitive attention problems, along with associated impulsive and distractible behavior. 2,3,4. To illustrate the characteristic impulsive thought patterns associated with ADHD: A child to whom I was administering some psychoeducational tests one day in a highly structured, one-on-one situation said to me, very suddenly, and totally unrelated to our conversation, "Hear the gold fish?" It turned out when he explained the chain of associations to me that when he heard a background noise in our testing room coming from the refrigerator in an adjoining room which had kicked into the defrost cycle, the electric fan which came on sounded just like the aerator in his aquarium at home, which of course contained fish. That's an example of the distractibility and impulsivity, holistic, insightful, lightning-fast association processing that often occurs with ADHD. We were doing well working one-on-one, highly structured, and all of a sudden he heard gold fish. That is how fast his mind jumped from one seemingly unrelated association to another, in terms of processing information. Aside from impulsive thinking, part of the complexity of ADHD is the cognitive quirk of "getting caught in a loop;" doing something over and over again. Often, with ADHD we see this "perseverational quality" that teachers are

familiar with where the child has to do something over and over again, getting stuck, for example, working over when he is erasing or crossing something out, apparently unable to stop marking when sufficiently erased or marked out. Note the similarity and overlap with the repetitive aspect of the first dimension.

Third Dimension

We have talked about the first dimension of motor tics, vocal tics, cognitive tics and sensory involvement, and then the second dimension, or layer, of ADHD involvement often present. Next, we shall explore the aspect of obsessive-compulsive disorder, (OCD) or ritualistic behavior, the third dimension often present in Tourettes. Though most literature refers to OCD, we like to call it more ritualistic than obsessive-compulsive because the term OCD traditionally connotes a psychological basis and associated anxious, neurotic involvement. These children don't typically have the associated anxiety that the psychological diagnosis OCD traditionally has. The child is compelled to perform tics and rituals not out of anxiety, but strictly from a basis of neurology. This is the child the parents report comes home from school, goes into his room, thrashes around, makes a lot of noise and then comes out of his room and says, "There, now I'm fine; I am going out to play." Another example to relate: One young man we know was reminded by his mother to go put water in the dog's dish in the backyard, as it was a hot August afternoon. He walked outside and around to the back of the house and filled the dog's water dish as instructed. When he came back in after filling it, he said, "Oh mom, I just walked around the house to the left; now I have to walk around the house to the right to make it even." And he laughed about it, slightly irritated at having to complete the ritual, but not in the least suffering anxiety about it. Where anxiety does become a part of ritualistic behavior is when, in school, for example, the child is caught up in a ritual of needing to count the dots in a ceiling tile. The teacher, noticing off-task behavior, says, "I thought I told you to get out your work and get busy." Children often tell us, as well as their parents, about how they have to work so hard that sometimes it hurts because their minds make them work all day long, just in following ritualistic thoughts. When children are necessarily called back to task, this is the point where anxiety understandably enters into the obsessions and compulsions, the ritualistic behaviors, of Tourettes.

Fourth Dimension

In addition to motor, phonic, and cognitive types of tics we have probable ADHD involvement, and then possibly obsessive thoughts, and the compulsions to perform ritualistic behaviors. Is the complexity of this disorder becoming apparent? Now to expand on the subject of ritualistic behaviors: Just as it was explained that the child gets caught up in doing something over and over again in ritual, that ritualistic behavior in some children spills over on a continuum into what is often referred to as stereotypical behavior, a type of behavior found in a variety of neurological disorders, but most commonly associated with autism. In Tourette Syndrome, there seems to evolve from this repetitive, ritualistic behavior what appears to be a sensory enjoyment of the behavior. Similarly, in autism one often sees animation and facial expression which conveys a sensory enjoyment similar to the sensory involvement one also sees in Tourettes. There are also instances of toe-walking and echolalia seen in conjunction with Tourette Syndrome. However, autism and Tourette Syndrome are two distinctly different conditions. Though there does appear to be this overlap of TS and autism symptomology in some individuals, there is a distinct and basic difference. In autism, one's sense of self is not developed. In TS, one does indeed possess a normally-developing sense of self. Hence, the painful embarassment that often accompanies these strange-looking behaviors.

Fifth Dimension

To build further on the layering conceptualization of Tourettes, at this point we have a child with motor and vocal tics, the complication of the hidden cognitive tics, then add on the associated ADHD involvement, the ritualistic behaviors, and the tendencies toward stereotypical behaviors that may be present. Now to explore the educational implications and the associated learning disabilities that are often present: One sees a greater proportion of children with Tourettes with associated learning disabilities than would be found in the general population 6. On traditional psychoeducational test batteries the intelligence scores are generally in the average range. The area that seems to break down fairly consistently, according to research, is visual-motor development. Typically the child's work will look rather sloppy or messy. Note this may be inconsistent with his level of measured intelligence and/or achievement, which can easily but perhaps erroneously be translated into an attitude problem on the part of the student. We've got one transparency here. This was a young man who was almost 14 years of age, extremely bright. He is in a gifted program and a regular classroom, and this is his homework. If I am the teacher and I know this student's academic potential and the student turns this in, I will probably say, "Try that

again, that is too sloppy; I can't read it." You can see here excessive marking out and erasures, an example of that getting caught into a ritual, or "loop" of doing something, and "my mind won't stop doing this and it makes my body keep doing it and I can't stop it and I have a hard time breaking that cycle." Because of this visual-motor delay, there is also an associated, very legitimate slowness in copy work, consistently reflected on the Coding subtest of the Wechsler Scales. Typically, full-scale scores will be in the average range on the Wechsler but you will see the Coding subtest score significantly reduced. When you translate that subtest score to a visual-motor age, the research cites that there is on average a year and a half discrepancy between visual-motor age and chronological age.7 With math, there typically is a disparity between written and verbal performance. In children with Tourettes, this is apparently due to the visual-motor responses required in written math. In reading performance, there is no remarkable pattern that exists in the literature or the research addressing Tourettes.

Now be aware that just as I am saying all this is Tourettes, some children don't exhibit each and every dimension or layer. And what is exhibited will be exhibited in varying levels of severity, ranging from mild to moderate to severe.

To further clarify, also bear in mind that one paradoxically consistent factor of Tourettes is that symptoms wax and wane, or change over time. Dimensions of the disorder will cross over each other, as well as change in intensity. That is the nature of the disorder. Hopefully, if you have followed the layering concept of Tourettes, by now you may appreciate that this is a child who truly can be an enigma for the teacher. If you are boggled by the immense complexity, you are probably understanding what Tourettes really is--a neurobehavioral disorder. This will dictate the need for flexibility and the allowance of creativity in educational planning. In short, it calls for the application of the highest art of teaching. It also calls for a highly individualized educational program, tailored to fit the individual student. There is no one "Tourette Syndrome IEP" which will work for all students with TS.

EMOTIONAL OVERLAY

Anxiety increases the symptoms and so does fatigue. Medications are available, which typically reduce the symptoms, but some children report to parents or teacher, "When I take this, it makes me fall asleep in class and so I would rather have my tics." Obviously the child experiences embarassment in having the disorder, and sometimes depression goes along with that embarassment. Letting the child know that you understand and accept that he has this

extremely complex disorder is paramount because the support systems i.e. the parents, teacher, and peers are extremely important to the development of this child's self-esteem. The child in constant fear of betrayal by his body will have difficulty building a positive self-concept. He will quite naturally rely heavily on positive feedback from significant others, during his formative years in school. Importance of support and understanding from significant others, including teachers, cannot be overestimated, because the child's ability to cope with the life-long intrusion of Tourettes, as well as his subsequent ability to function in society is largely determined by the degree and constancy of this support.

CLASSROOM INTERVENTIONS

The following classroom recommendations are provided for your use in working with a student exhibiting Tourettes.

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EDUCATIONAL RECOMMENDATIONS FOR CHILDREN WITH TOURETTE'S SYNDROME

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A. ENVIRONMENTAL STRUCTURE AND PLANNING

1. Set and communicate behavioral and academic expectations to students. (However, keep in mind flexibility is required.) Use of behavior modification techniques - use of positive reinforcement, contracting and explicit rules and consequences helps with limit setting.

2. Allow student to work at own pace if he can stay on task.

3. Allow for ample space to move about freely.

4. Allow for a refuge if symptoms become severe. On occasions when student needs to leave class because of tics, a discreet signal can be worked out between student and teacher. Be careful not to send student out on regular basis. Student can have someone tape (audio) what he or she misses.

5. If possible allow child to monitor his own need for removal from class (voluntary time-out).

6. Quiet time or study hall can be extremely stressful when focal tics are present. Concentration required to control vocal tics diminishes concentration and attention to task.

7. Tics tend to be worse toward the end of the day. Increased energy and effort spent controlling tics makes concentration difficult. Therefore, plan academics accordingly.

8. With the waxing and waning of symptoms, structure must be varied, sometimes on a daily basis, to provide an appropriate educational environment. This will be a challenge for the teacher.

9. Probability for small student-teacher ratio, a resource room setting may be appropriate under category of Other Health Impaired (OHI/P.L.94-142).

10. Flexibility in IEP may be appropriate due to waxing and waning of symptoms.

11. Communicate and work closely with parents to allow for adequate social and emotional growth.

B. VISUAL MOTOR IMPAIRMENT

1. Remember, pencil use may be slow and laborious due to involuntary pushing too hard, work-overs, repetitive erasing, etc.

2. Restrict or limit motor involvement; with problems involving pencil and paper tasks, alternatives such as dictation, typing microcomputer programs, word processing programs, prewriting programs, and verbal responses are suggested (Word processor-first draft is their final draft).

3. Provide for non-academic psychomotor activities, such things as art work, model building, video games, sewing, gross motor play activities, etc.

4. Photocopy or otherwise reproduce materials rather than require copying tasks. Copying from board is extremely time consuming and frustrating.

5. Allow use of 3"x 5" card for visual tracking.

6. Consider use of calculators, and tutoring for arithmetic. WISC-R vs. WRAT-Arithmetic - Oral vs. Written.

7. Allow more time for written and copy work or reduce the length of the assignment.

8. Tape lectures and allow for extended time and/or oral response to tests.

9. Allow use of NCR paper so peer helper can provide copy of notes to student with T.S.

10. Turn lined paper sideways, allowing for column alignment for long division and 2 or 3 digit multiplication work.

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C. ATTENTION DEFICIT DISORDER, IMPULSE CONTROL (ADHD)

1. Repetitive thougn patterns of an involuntary nature may cause child to "dwell" for a length of time unnecessarily on a math problem, or in reading tasks on a particular sentence in a paragraph. This may be exhibited as excessive proofreading, rereading a paragraph, checking of work, or continued tracing of object with eyes. We believe this happens because thought processes don't progress sequentially, but get "caught" in a loop," (mental tic).

2. Provide for many social experiences and opportunities to function with other children since social maturity may be delayed. Structure group work by assigning specific tasks to members. Facilitate cooperative vs. competitive tasks with others.

3. Due to impulsive behavior, it is strongly recommended that the child be taught basic study skills (SQ3R), and organizational strategies such as: (a) how to remember (b) how to sequence tasks, breaking them down into manageable steps, (c) how to study.

4. Whenever possible, utilize concrete rather than abstract approach to teaching concepts.

5. Whole word (decoding) or cluster approach to reading in conjunction with strict phonetic approach) is recommended. Such approaches as Glass Analysis utilizing clusters in words is strongly advised.

6. Visualized notemaking, "Weighing the evidence."

7. While engaged in academic task, child may need to simultaneously be involved in some type of motor behavior - foot tapping (no shoes), seems. to meet sensory need associated with T.S.

8. Seating considerations.

9. Structure assignments. Delineate on paper what is expected - short lessons with assured completion. This allows for feeling of closure which helps improve self-concept.

10. For caught in-a-loop "obstinacy" in younger children, play "Okay I Will."

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D. OBSESSIVE COMPULSIVE SYMPTOMS, RITUALISTIC BEHAVIOR

1. Redirect:
   a. Use of timer
   b. Use of name
   c. Proximity, eye contact

2. Incorporate relaxation techniques, systematic breathing, visual imagery, visual self-modeling, role-playing and auto-suggestion.

E. COGNITIVE AND LEARNING DISABILITIES

1. Learning and memory - best result with general concepts, or overview first, before presentation of specific facts. If learning of specific facts is needed, use demonstration, provide experience, incorporate audio-visual approach, or allow child to perform in order to process information. Overview before proceeding with specifics reduces impulsivity because the structure has already been addressed. Present whole scope of new concepts so that child will know where he is to go with information - where to plug it into his experience.

2. Interactive computer programs for drill and practice or tutorial programs, (watch for stimuli overload).

3. Learning style may be holistic and deductive rather than sequential and inductive. Therefore, bibliotherapy vs. lecture format may be more satisfactory.

4. Role-playing and provision of experience will facilitate learning. Make tasks concrete wherever possible by providing manipulative objects, models, pictures, diagrams, etc.

F. EMOTIONAL OVERLAY

1. Remember the incredible power and responsibility of the teacher as acceptance model.

2. Work to enhance self-concept. This point is extremely important. Student may act as an aid or tutor to younger child. A feeling of self-worth will ameliorate many obstacles.

3. Child in constant fear of betrayal by his body will have difficulty building a positive self-concept. He will quite naturally rely heavily on positive feedback from significant others, on an ongoing basis, during school years.

4. Again, teach use of relaxation techniques, visual imagery, and auto-suggestions to enhance self-concept and sense of control.

5. Peer-tutoring or peer-helping can help to improve self-concept.

G. TESTING CONSIDERATIONS

1. Eliminate stress-provoking situations, i.e. timed tests.

2. Separate area for testing allows the student to "release" tics without fear of disruption.

3. SAT and ACT testing can be negotiated with respective companies without violation of standardization procedures.

4. Machine-scored answer sheets (bubble type) are extremely difficult for people with visual-motor problems. Allow for alternatives.